ASCO COVID-19 Registry Data

Description

The American Society of Clinical Oncology (ASCO) Survey on COVID-19 in Oncology Registry (ASCO Registry) aims to help the cancer community learn more about the patterns of symptoms and severity of COVID-19 among patients with cancer, as well as how COVID-19 is impacting the delivery of cancer care and patient outcomes. The ASCO Registry is designed to collect baseline and follow-up data on how the virus impacts cancer care and patient outcomes during the COVID-19 pandemic and for up to two years after a patient with cancer is infected with SARS-Cov-2.
ClinicalTrials.gov: NCT04659135

Project Overview

The ASCO Registry aims to capture and describe cancer and SARS-CoV-2 infection status at the time of SARS-CoV-2 confirmed infection, during acute SARS-CoV-2 infection phase, and for lingering SARS-CoV-2 infection symptoms and sequelae (as relevant), as well as cancer and SARS-CoV-2 infection outcomes.

Patients eligible for inclusion in the ASCO Registry meet the following two inclusion criteria:
1) A positive SARS-CoV2 test or clinically diagnosed COVID-19
2) One of the following must be true at the time of SARS-CoV2 positivity:
   a. The patient has active cancer
   b. The patient has been disease-free for less than 12 months (i.e., from the time of surgical resection or complete remission) and is receiving adjuvant cancer therapy

Data collected include cancer treatment approaches at the time of SARS-CoV-2 infection, cancer status at the time of SARS-CoV-2 infection, changes to cancer treatment plans, the status of SARS-CoV2 infection (e.g., the severity of symptoms, need for ventilator, hospitalization, recovery, long-term symptoms, and sequelae, etc.), vaccination information, and change in cancer status (e.g., cancer progression, treatment-related changes/modifications, etc.).

More information can be found in the study schema and protocol.

Why is this data important; what makes it unique?

The COVID-19 pandemic presents a unique opportunity to capture information on how a disease outbreak affects the delivery of high-quality cancer care. ASCO provides the means for the oncology care community to submit data that will inform both current cancer care and provide information to help guide decision-making for future disease outbreaks. While other entities have launched COVID-19 cancer registries, ASCO has extensive relationships with the entire cancer care community, particularly private practices that may be caring for the majority of U.S. cancer patients with COVID-19 and have partnered with ASCO to provide this data for the ASCO Registry.
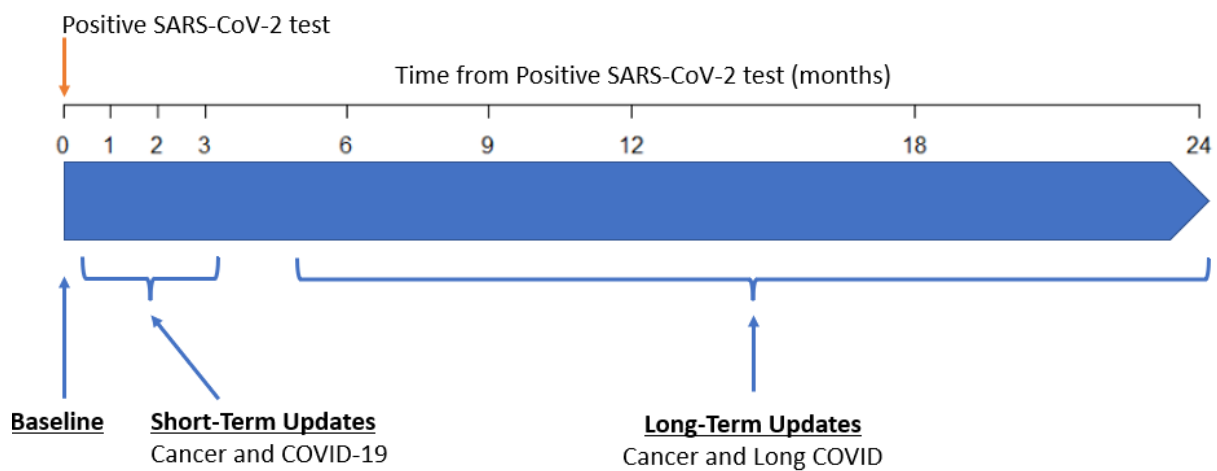
Is the data available elsewhere?

This is an ASCO data source and is not available elsewhere.

Design

ASCO's registry collects information about patients undergoing treatment for cancer and with confirmed SARS-CoV-2 infection based on a positive test. Unlike other registries, ASCO's registry collects follow-up information on SARS-CoV-2 infection and cancer outcomes at 30-day intervals for the first 90 days, 90-day intervals up to one year, and at 18- and 24-months after a positive SARS-CoV-2 test.

ASCO Registry Study Design and Data Collection Points

Positive SARS-CoV-2 test

Time from Positive SARS-CoV-2 test (months)

0 1 2 3   6   9   12   18   24

Baseline

Short-Term Updates
Cancer and COVID-19

Long-Term Updates
Cancer and Long COVID

ASCO® CENTRA
Center for Research & Analytics

Study Calendar for Patients in ASCO Survey on COVID-19 in Oncology Registry

Phase	Initial Entry	Short term Follow-up			Long-term Follow-up
	Initial at time of SARS-CoV-2 infection	1 month after SARS-CoV-2 infection	2 months after SARS-CoV-2 infection	3 months after SARS-CoV-2 infection	6, 9, 12, 18, and 24 months after SARS-CoV-2 infection
Initial Entry:					
Initial Clinical and Demographic Information	●				
SARS-CoV-2 infection Symptoms, and treatment	●				
Cancer Diagnosis, Status, and Treatment	●				
Short Term Follow-up					
SARS-CoV-2 infection Update		●	●	●	
Cancer Status Update		●	●	●	
Long Term Follow-up					
SARS-CoV-2 infection Long-term Update					●
Cancer Long-term Update					●

Variables

In general, the data includes:
- Demographics (e.g., gender, race, ethnicity, age at COVID-19 diagnosis, type of cancer, and comorbidities)
- SARS-CoV-2 infection status (e.g., symptoms, sequelae, treatments, vaccination status, and outcomes)
- Cancer status (e.g., treatment plans, any changes to treatment plans, and response to treatments)
- Information on patient and practice geography is limited to U.S. Census Region. Area-level variables pertaining to the rurality of practice location and patient residential area and Social Determinates of Health factors are also included. These variables are categorized at the national level and linked to the Registry data by patient and/or practice zip code before zip codes are removed from the research files to preserve patient confidentiality (see Limitations).

Review sample data collection forms here:
- ASCO Registry Form Selection
- Patient's Baseline Demographic, COVID-19, and Cancer Information
- Acute COVID-19 Follow-Up

ASCO® CENTRA

Center for Research & Analytics

- Long-Term 6, 9, 12 month COVID-19 Follow-Up
- Cancer Treatment and Status Follow-Up
- Long-Term 18 and 24 month COVID-19 Follow-Up

Sample Size/Number of Respondents

ASCO's Center for Research and Analytics (CENTRA) has created an online data dashboard (https://www.asco.org/asco-coronavirus-information/coronavirus-registry/covid-19-registry-datadashboard) that is routinely updated. The ASCO Registry Dashboard summarizes data in the overall cohort and includes an interactive mechanism to stratify the cohort by patient characteristics, such as cancer types and extent, age, race, ethnicity, gender, smoking status, SARS-CoV-2 infection symptoms, and comorbidities. As of April 4, 2022, the ASCO Registry had at least the baseline visit information (i.e., demographics, risk factors, and cancer and COVID-19 information at initial infection) entered on more than 5,965 patients.

Data Formats

The patient-level clinical data tables are in Comma Separated Value (CSV) files. Randomized patient identifiers are included in each table to allow linkage. In addition, tables are organized by visit type (baseline vs. follow-up) and data type (risk factors and demographics, COVID-19, and cancer).

Limitations

- The dataset is de-identified using the expert determination method. All HIPAA Safe-Harbor identifiers are removed from the data sets, except for certain elements of dates. Some dates are shifted to the Sunday of the relevant week (e.g., COVID-19 diagnosis date, cancer diagnosis date, date of COVID-19 hospital admission). In contrast, other dates are provided as day intervals from unshifted index dates (e.g., number of days in the hospital—from the actual date of admittance to the actual discharge date).
- Because this is an observational study, ASCO does not direct practices to capture any information not already recorded in the patients' oncology practice EHR data – except COVID-19 treatment and inpatient information (where relevant). Most oncology care providers are not treating COVID-19 in their cancer patients. Thus, a detailed accounting of all relevant COVID-19 symptoms, treatments, and sequelae may not be present in the oncology practice EHR. Common elements collected in clinical trials are sometimes recorded in patients' EHRs, but researchers should expect missingness or "unknown" reported for inconsistently collected variables in patient records.
- Data forms are subject to availability for each patient. The follow-up form was not submitted if updated data was not available for a patient for a specific follow-up.

Data Codebook

Please see the codebook document.

ASCO® CENTRA
Center for Research & Analytics

Data Structure

Researchers will receive seven analytic data tables that can be linked together with a random patient identifier.

Analysis Table Name	# Variables/Table	Examples of Variables:
Risk Factors	71	• Age category at the date of COVID-19 diagnosis • Gender • Smoking status • Information on comorbidities
COVID-19 Baseline	96	• Date of positive COVID-19 test (shifted to the Sunday before) • Date of 1st COVID-19 vaccination (shifted to the Sunday before) • Date of admission to the Intensive Care Unit (shifted to the Sunday before) • COVID-19 symptoms
Cancer Baseline	128	• Cancer type (ICD-10 code) • Cancer extent at the time of COVID-19 diagnosis • Date of initial cancer diagnosis (shifted to the Sunday before) • Cancer treatments the patient was receiving or scheduled to receive at the time of COVID-19 diagnosis
COVID Acute Follow-up	93	• Dates of COVID-19 vaccine injections (shifted to the Sunday before) • Receipt of anti-COVID-19 drugs • COVID-19 symptoms
COVID Long-term Follow-up (6, 9, and 12 months)	41	• ECOG performance status at most recent clinical encounter • Dates of COVID-19 vaccine injections (shifted to the Sunday before) • COVID-19 symptoms
Cancer Follow-up	54	• Primary cancer currently being managed (ICD-10 code) • Anti-cancer drug information • Cancer treatment delays, discontinuations, and dose modifications
COVID Long-term Follow-up (**18 and 24** month)	84	• COVID-19 symptoms • Smoking status • Dates of COVID-19 vaccine injections up to 3rd injection (shifted to the Sunday before)